Transplant Outcomes Report

Heart • Kidney • Liver & Intestinal • Lung & Heart-Lung • Multi-organ

Stanford Children’s Health | Lucile Packard Children’s Hospital Stanford
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The Pediatric Transplant Center at Stanford Children’s Health specializes in all pediatric solid organ transplants, including heart, liver, kidney, intestine, and lung transplants, as well as combination transplants such as heart and lung, heart and liver, and liver and kidney.

Decades of successful organ transplantation experience give us a solid foundation from which to best help nearly 100 children needing organ transplants each year. We continue to innovate surgically, medically, and in every way we can to improve the quality and length of our patients’ lives. Stanford’s providers, scientists, and engineers collaborate across many disciplines to chart the best course forward for each patient but also for the field itself. As this report demonstrates, our approach has achieved some of the best outcomes in the country for the more than 2,000 transplants we have conducted since our founding. Many of these transplants were for the youngest, smallest, and most acutely ill organ-failure patients.

Researchers at Stanford have long explored and deployed new ways to manage the rejection of transplanted organs. Today, investigators in our immunobiology research laboratories, in collaboration with the Institute for Immunity, Transplantation, and Infection (ITI), are conducting studies to better understand how the immune system defends the body at a molecular level. Our immunologists, pathologists, microbiologists, infectious disease experts, surgeons, and transplant specialists are examining immunological puzzles from every angle, a methodology that fuels collaborative innovation and, ultimately, improves the care we provide and the longevity and quality of life of our patients.

We also understand the disruption and stress that accompany serious pediatric illness, and we do everything we can to allow children and their families to focus on healing—and on each other. Major advances in telemedicine, some accelerated in response to the mandates of the COVID-19 pandemic, have also improved the quality of life of our patients, allowing them to do from home what was once only possible at an in-person visit. Moreover, when necessary, our transplant coordinators help arrange medical flights for children who are too sick for ordinary travel, and they also facilitate accommodation for families who sometimes must stay near the hospital for weeks or months. We quickly mobilize our experienced teams to prepare a patient and family for an organ transplant.

Our teams follow up with transplantation patients and their local doctors, even as the patients mature. Some patients transition to adult care at Stanford, but they each remain in our extended family of transplantation alumni. All of this together accounts for the extraordinary outcomes highlighted in this brochure and the unequaled experiences of our patients and families as well as their referring physicians.
Heart Transplant Program

“...Our depth of experience attracts the most difficult and complex cases, including many turned away by other centers. Nonetheless, our survival rates and other metrics of success are among the best in the world."

—David Rosenthal, MD
Heart Transplant Program Overview

Stanford’s heart transplant program is one of the oldest and highest-volume heart transplant programs in the United States, and its legacy is punctuated by firsts and bests. The first successful human heart transplant in the United States was conducted here in 1968 by Norman Shumway, MD, PhD, and his surgical team. Sixteen years later, Dr. Shumway accomplished the first successful transplant of a 2-year-old in the United States. Our youngest heart transplant patient to date was only 15 days old. In 2004, Stanford’s David Rosenthal, MD, launched the Pediatric Advanced Cardiac Therapies (PACT) program, the nation’s first combined heart failure, VAD, and transplant program dedicated to children, marking a paradigm shift in heart patient care and becoming a model for programs across the country. “Recognizing that the same patients were moving from the heart failure program to the transplantation program and that many of them at some point required ventricular assist devices (VADs), we brought pediatric heart failure, VADs, and transplant all together. We knew we would get better outcomes by focusing on the evolving patient instead of just one stage of a disease,” says Dr. Rosenthal, director of PACT.

Since its inception, our program has conducted nearly 450 pediatric heart transplants, a depth of experience that attracts the most difficult and complex cases. Nonetheless, our survival rates and other metrics of success are among the best.

We also are pushing back frontiers on the medical management of immune responses, protocols for managing coagulation and preventing stroke in heart failure and VAD patients, and the development and application of VADs for all kinds of pediatric heart patients, including a growing number of single-ventricle patients who may then go on to have heart transplants.

Our approach to treating antibodies against transplanted hearts gives us a remarkably low rate of organ rejection. And, with our TEAMMATE trial, immune-response management protocols are currently the subject of the first randomized and controlled multicenter study of anti-rejection therapy in children who have received heart transplants. Identifying protocols for preventing rejection boosts longevity and quality of life for all heart transplantation patients.

Another central component of PACT is the Pediatric Cardiomyopathy Program. “About one-third of the patients who enter that program because of their various heart problems will eventually be considered for transplant, so close coordination between the cardiomyopathy, VAD, and transplant teams is key,” says cardiologist Beth Kaufman, MD, director of the program. She and her colleagues work with multidisciplinary teams, including the Metabolic and Neuromuscular programs and the Center for Inherited Cardiovascular Diseases, to uncover the etiology of their young patients’ heart problems. That sometimes pays off, too, for the patients’ relatives, who may not be aware that they share a dangerous genetic condition.

Our pioneering work in the treatment of single-ventricle patients is another example of the benefits of our comprehensive, interdisciplinary approach. The Fontan procedure, an innovative surgical technique used for some single-ventricle patients, extends the lives of many patients. Creative application of VADs and improvements in the medical protocols applied to young children and infants allow many of those patients to live long enough not only to qualify for the heart transplant list but to gain strength while they await a suitable organ.

Our physicians sometimes use VADs together with cardiac medications to allow an ailing heart to recover and even, in some cases, to avert the need for transplant. “But, if transplant does become necessary,” says Seth Hollander, MD, medical director of the Heart Transplantation Program, “we know the patient very well and can give them the best uninterrupted care, even as their treatment enters a new stage.”
Heart Transplant Program Milestones

Ongoing participant in the first-ever collaborative study, funded by the National Institutes of Health, of the mechanisms of chronic allograft rejection in pediatric patients.

Innovative care program for heart failure and transplant patients who are highly sensitized.

We have performed 440+ pediatric heart transplants.

We have implanted over 160 VADS.

One of the highest-volume pediatric ventricular assist device (VAD) programs in the United States.

National leader in pediatric combined heart-liver transplants in the United States.

More than 35 years of experience performing pediatric heart transplants.
Heart Transplant Program Data

Stanford Children’s Health has an extraordinary VAD program that helps keep our young heart-failure patients strong enough to qualify for, and alive long enough to receive, a suitable transplant. In 2019, all eight of our patients that used VAD as a bridge were successfully transplanted. Three of those children were complex single-ventricle cases that most centers would not have been equipped to help.

Not a single patient that made it onto the heart transplant wait list perished in 2019. That remarkable mortality rate is partly due to our shorter-than-average wait times, our expertise managing VAD as a bridge to transplant, and the extraordinary medical attention we give to each patient in our heart program.
Heart Transplant Program Data

Our surgeons and cardiologists specialize in the smallest and most difficult cases, many of which have been rejected for transplant by other centers. While most of our patients are between the ages of 11 and 18, we transplant an extraordinary number of children younger than 1 year old. Our youngest heart transplant patient was only 15 days old. The innovative use of ventricular assist devices (VAD) helps us keep our youngest and smallest patients alive until a suitable transplant organ is found for them.

Most of our heart transplants are conducted on single-ventricle patients, and about half of them are younger than 10 years old. Congenital heart disease patients with a single ventricle present a special challenge for transplant. “Most centers won’t use VADs for their single-ventricle patients,” says Pediatric Advanced Cardiac Therapies (PACT) program director David Rosenthal, MD. “The complexity is such that they just don’t want to take that kind of risk. We aren’t daunted by the tough cases.”
15-Year-Old Heart Transplant Patient Creates Cookbook With Heart-Healthy Recipes

At just 15 years old, Justin Wang has already built a bucket list of the things he wants to see and do in his lifetime. That’s because for Justin, health complications, including needing a heart transplant, have been part of his life for as long as he can remember.
When it comes to the kidney allocation system, we are focused on kids. We stay engaged at the national level to ensure we can provide the best service for children and ensure they get exactly what they need for their growth and development.

—Amy Gallo, MD
Kidney Transplant Program Overview

Since its inception 20 years ago, Stanford Children’s Health’s kidney transplantation program has performed over 650 kidney transplants, more than any other pediatric program in the United States.

Many of the children we transplant are very small and young, and some have vascular damage or other serious health problems before we meet them. Yet, because of our extraordinary expertise, we are able to accept the most complex and acute cases, including many that have been deemed un-transplantable by other centers. Even so, our one-year and three-year pediatric kidney transplant patient survival rates are an unsurpassable 100 percent.

One key to that success is a “total body, total patient” approach to treatment. Each patient’s neurological, cardiovascular, immunological, and emotional development are considered as we pursue the best possible conditions for transplant. “We get the soil as close to perfect for that child as possible, so the transplanted kidney can best take root and flourish,” says Paul Grimm, MD, medical director of the Pediatric Kidney Transplant Program.

The program also takes an advanced and nuanced approach to immunosuppression, closely tailoring treatments to each patient’s genetic and medical needs. For example, we have developed a steroid-free rejection-prevention protocol that, for some patients, is just as effective as traditional steroid-based ones but spares the negative side effects of steroids.

Because of our program’s renown, we attract the world’s best care providers. We are always on call and ready to ensure a seamless procedure whenever a patient is ready and a kidney becomes available. “Our surgeons and physicians live and breathe pediatric kidney transplant,” says Dr. Grimm. That focus and purpose are there before, during, and after the surgery itself. We work closely with referring nephrologists throughout the region to prepare their patients for transplant and then, when they are ready, to bring them to Palo Alto for surgery. As soon as it is safe, we help patients return home again to recover in their own communities and under guidance of their own physicians. If questions or complications arise, we are always available for consultation and can quickly return a patient for further surgery or other interventions. “We track all of our patients, stay in close touch, and are here for them and their physicians along their entire journey,” says Dr. Grimm.

Remarkable new treatments are emerging from a collaboration between the pediatric stem cell transplant program and the kidney transplant team. In some cases, a parent can now donate both a kidney and stem cells to a child patient. Once a child’s immune system has been replaced with a parent’s, there is no longer need to immunosuppress; the child’s new kidney is accepted by the body as if it were native. We have high hopes that this approach will eliminate for these patients the risks of rejection and subsequent kidney failure as well as eliminating immunosuppression-related infections and cancers.

As children mature and parents gradually relinquish the supervision of their children’s medication, potentially lethal nonadherence mishaps become more likely. So, we work with patients and parents to reinforce the importance of compliance, but we also are developing new immunosuppression regimens that provide safety nets for patients during adolescence.
Kidney Transplant Program Milestones

100%
1-to-3-year patient survival

National leader in pediatric combined liver-kidney transplants

We have performed more than 650 pediatric kidney transplants.

Over the past 5 years, we have performed more pediatric kidney transplants than any other U.S. program and are #1 in survival outcomes.

We have performed transplants in recipient children from Canada, Peru, Kuwait, and 28 U.S. states.

More than 20 years of experience

4th in the nation for nephrology


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Kidney Transplant Program Data

Stanford Children’s Health conducts by far the highest volume of pediatric kidney transplants in the field and has the lowest hazard ratio, or survival analysis, in the first year after transplant. Our hazard ratio is significantly below 1. A hazard ratio of 1 signifies the statistical average, given the age, diagnosis, and condition of the patient. The lower its hazard ratio, the better an organization is doing relative to the average.

Three years after transplant, Stanford Children’s Health’s hazard ratio is even lower than after one year, reflecting our expertise and supreme team effort in every stage of the transplantation process, including our close communication and collaboration with patients and referring physicians in the months and years following transplantation. Again, when it comes to hazard ratios, lower is better.
None of Lucile Packard Children’s Hospital Stanford’s patients died while awaiting a kidney, a stark contrast with other centers. This success reflects both the program’s extraordinarily short wait times and its emphasis on caring for every aspect of the patient’s health until a donated kidney is available for transplant.

The Possibilities Are Endless—Just Like Shriya’s Love for Life

Our doctors performed a groundbreaking double transplant to treat Schimke immuno-osseous dysplasia (SIOD) in Shriya, age 9. This novel approach gave her a new immune system that recognized her new kidney, eliminating the need for anti-rejection drugs.
Liver and Intestinal Transplant Program

We envision a future when children do not have to face a lifetime of immunosuppressive drugs with all the undesirable side effects, or die waiting for an organ. Indeed, we foresee an era of advanced medicine when we can renew function to diseased native organs with regenerated tissue or replace them with bioengineered organs.

—William Berquist, MD
Liver and Intestinal Transplant Program Overview

Stanford Children’s Health’s transplant team has performed more pediatric liver transplants over the past five years than any other center in the western United States. Our patients are among the most acutely ill and complex in the country, and we are pleased that we still can provide the best care to ensure great long-term outcomes. That record is attributable largely to the extraordinary “clinical breadth, depth, and coordination of a team that continually seeks to improve patient outcomes and experience,” says surgeon Carlos O. Esquivel, MD, PhD, director of the Pediatric Liver Transplant Program. Also key to that success, our unique outreach program regularly takes our team to 10 different sites around the West, keeping us in close touch with our patients and ensuring that they get excellent care long after their surgery.

We emphasize treating the whole person. For example, in collaboration with the Division of Adolescent Medicine, hepatologist William Berquist, MD, created an innovative program that helps teenagers with transplants better care for themselves. Teenage patients are at higher risk of missing medication dosages as they transition into adulthood. This is a particular problem when working with a patient with an organ transplant. “Unless they take their medications, a patient’s transplanted organ is going to fail,” Dr. Berquist says. The transplant center helps transition patients to an adult program by cultivating strong relationships with—and between—patients and by helping parents support their adolescent children.

We also excel at sustaining ailing livers until donor organs are available. Our living-donor program smooths the way for relatives and close friends to give portions of their livers to loved ones in need, shortening patients’ waiting periods. The median national wait time for a liver donation is more than seven months longer than it is at Lucile Packard Children’s Hospital Stanford.

Young liver cancer patients have many more options than they did just a few years ago. Progress in chemotherapy, interventional radiology, hepatology, surgical techniques and transplantation have all benefited these patients, leading to longer and better lives and to reductions in transplants.

Over the past decade, successful rehabilitation and medical management of intestinal disorders has led to a decline in the need for intestinal transplantations. For example, the use of ethanol locks has reduced line infections, which were historically a major obstacle to long-term total parenteral nutrition (TPN) use. New lipid formulations have also led to reductions in the incidence of liver damage from prolonged TPN use; some patients even remain on TPN into adulthood, avoiding transplantation until their 20s. These and other advances allow us to successfully bridge new kinds of patients to intestinal transplantation. “For those patients who eventually do need transplants, there are more options today than ever before,” says Andrew Bonham, MD, surgical director of the Intestinal Transplant Program.

“TPN management is only one area where our participation gives a real advantage to our partners in the field,” says Dr. Bonham. Lucile Packard Children’s Hospital Stanford researchers also discovered that “intestinal grafts are more sensitive to antibody-mediated rejection than originally thought,” he says. “The outreach team works hard with local physicians to manage that and keep these kids healthy once they get home, whether they have received a transplant or not.”
Liver and Intestinal Transplant Program Milestones

Median liver transplant waiting time

2.7 months at our hospital compared with 10.1 months in the nation

Intestinal Transplant Program with

100% graft and patient survival since 2014

We have performed over

800 pediatric liver and intestinal transplants

National leader in:

- Metabolic transplants
- High-Risk liver Tumors
- Combined heart-livers done en bloc
- Combined liver-kidney

Cutting-edge research in excellent outcomes and patient care innovations: photopheresis, posttransplant lymphoproliferative disorder, tolerance induction, and laparoscopic living donation

More than 50 cumulative years of experience in our surgical team performing pediatric liver and intestinal transplants
Liver and Intestinal Transplant Program Data

Lucile Packard Children’s Hospital Stanford conducted nearly 80 liver transplants in the 2.5 years covered by this graph, making it the second-highest output center in the country. There were no deaths among all those patients in the first year after transplant, giving the center an excellent one-year survival hazard ratio of well below 1. A lower hazard ratio indicates a better performance.

Even more telling than the one-year survival in evaluating the long-term success of a program is the three-year rate. Lucile Packard Children's Hospital Stanford’s is again well below 1, even though we have the most patients, as well as many of the youngest, smallest, and most acute cases in the country. When it comes to hazard ratios, lower is better.
Liver and Intestinal Transplant Program Data

This data represents not only the survival of the patient after three years, but also the persistent integrity of the patient’s new liver. Again, not only does Lucile Packard Children’s Hospital Stanford do the highest volume of pediatric liver transplants, but also it has a hazard ratio of well below 1 for livers three years after transplant. The lower the hazard ratio, the better the performance.

One Donor Liver, Two Lives Saved

The lives of two patients—one a baby, the other a retired physician—crossed paths in the most unexpected way when a single organ donor helped save both their lives at once.
Stanford Children’s Health’s Liver and Intestinal Transplant Outreach Locations
Lung and Heart-Lung Transplant Program

“We communicate with children on their own level. If they understand what’s happening, they’re much more likely to cooperate and to join the team.”

—Carol Conrad, MD
Lung and Heart-Lung Transplant Program Overview

Most lung and heart-lung transplant centers are adult-oriented, but there are important advantages to treating young patients in centers like ours, where nurses, pulmonologists, anesthesiologists, surgeons, and other staff all specialize in the care of children. “It’s an advantage, for example, to have a pediatric surgeon who is experienced and comfortable working with smaller airways, smaller blood vessels, and smaller bodies in general,” says Carol Conrad, MD, medical director of the Pediatric Lung and Heart-Lung Transplant Program.

Our Pediatric Lung and Heart-Lung Transplant Program is an internationally recognized Center of Excellence. We treat young patients from around the world for a full range of diseases requiring lung or heart-lung transplants. We treat more young lung transplant patients than any other center on the West Coast. In our 30 years of experience, we have conducted 47 pediatric lung transplants and 36 heart-lung transplants.

Approximately half of our lung transplantation patients suffer from cystic fibrosis. Most of the others suffer from pulmonary hypertension. To achieve one of the best adolescent outcome rates in the world, our team works with experts in Stanford Children’s Health’s Pulmonary, Asthma, and Sleep Medicine and Cystic Fibrosis centers. Our Cystic Fibrosis Center’s multidisciplinary team offers respiratory therapy, nutritional counseling, diabetes treatment, psychiatry, and social work services. Ours is the only center in California, Nevada, or Oregon that has been designated a Therapeutic Development Network Center by the Cystic Fibrosis Foundation.

To maximize the life span of transplanted lungs, we balance controlling rejection with protecting our patients’ lungs from infection and scarring. That balancing begins in our Histocompatibility Lab (HLA), which helps match donated lungs to recipients whose immune systems will be least reactive to them. “Our ability to assess the degree to which a donor and recipient are compatible has improved exponentially,” says Dolly Tyan, PhD, one of the developers of the potent new generation of human leukocyte antigen screens now key to every Stanford transplant program, including the Lung and Heart-Lung program.

We also are seeking ways to improve early detection of the harmful lung scarring that is characteristic of cystic fibrosis. “We explore the mechanisms underlying rejection in efforts to extend the lives of transplanted lungs,” says Dr. Conrad. “Today, scarring often does irreversible damage before we are even able to detect it,” she says. To get sufficient data, our team collaborates with other transplant centers around the country looking for biomarkers of early lung scarring. Dr. Conrad led one study showing that a patient’s lung clearing index (LCI) provides more sensitive and nuanced measures of airway dysfunction than spirometry.

Stanford Children’s Health’s program has recently become the only pediatric lung transplant program accepting babies, toddlers, and even older children who have developed respiratory failure months or years after having been surgically palliated for congenital heart lesions. These children are generally extremely challenging from a surgical perspective, and they may have thoracic adhesions or extensive collateral arteries, placing them at high risk for intra- and post-operative complications and prolonged hospitalizations. We provide hope for the families of these children, who had little until now.
Lung and Heart-Lung Transplant Program Milestones

2011
First pediatric lung-liver transplant performed at our hospital

We have performed more than 85 pediatric lung and heart-lung transplants.

Ongoing participant in the first-ever collaborative study, funded by the National Institutes of Health, of the mechanisms of chronic allograft rejection in pediatric patients

1988
First pediatric heart-lung transplant performed at Stanford

More than 30 years of experience performing pediatric lung transplants

7th in the nation for pulmonology

Lucile Packard Children’s Hospital Stanford’s hazard ratio for one-year patient survival is just a little over 1, which is better than several other top centers in the field.

Heart-lung transplant patients at Lucile Packard Children’s Hospital Stanford waited only a couple of months for suitable organs, while the regional average wait time is longer than a year. The U.S. average is longer than five years.
Siblings With Double-Lung Transplants Beat the Odds

Siblings David and Doris Diaz both have cystic fibrosis and needed double-lung transplants. Doris had hers first, at age 8, and so she was able to help support David through his when he was 9. Pediatric lung transplants are rare, but Stanford Children’s Health’s extraordinary Lung and Heart-Lung program has been conducting them for more than 30 years.
We think of combined organ transplantation not as one patient getting two surgeries, but as one well-integrated, well-choreographed single therapeutic intervention that happens to involve two different specialties and two organs. —Paul Grimm, MD
Multi-organ Transplant Program Overview

Our extensive experience with pediatric heart, lung, liver, kidney, and intestinal transplantation has also led to specialized expertise in combined transplants with two or more organs, including heart-kidney, liver-lung, liver-intestine, liver-intestine-pancreas, liver-kidney, and heart-liver.

“At Lucile Packard Children’s Hospital Stanford we meet complexity head-on,” says Paul Grimm, MD, medical director of the Pediatric Kidney Transplant team. “We think of combined organ transplantation not as one patient getting two surgeries, but as one well-integrated, well-choreographed single therapeutic intervention that happens to involve two different specialties and two organs.”

For a growing number of patients, combined transplants are necessary because improved disease management has allowed them to live significantly longer than they once would have. For example, patients may now live long enough with a heart disorder that they eventually need a new liver as well as a new heart.

“Our mantra has been, ‘We’re happy to take on the kind of patients that other places will not,’” says Michael Ma, MD, the surgical director of PACT, who also conducts combined heart-liver transplants, mostly on teenage patients who have had single-ventricle palliation as young children and have had long-standing Fontan circulation, which eventually causes liver fibrosis. These patients are more and more often best treated with an en bloc, combined liver and heart transplantation.

The most common pediatric multi-organ transplant is the liver-kidney combination. Three main categories of children come to us in need of liver-kidney transplantation: those with autosomal recessive polycystic kidney disease or other diseases that cause irreversible kidney and liver damage, those with end-stage renal diseases caused by liver-based metabolic disorders such as primary hyperoxaluria, and those with concomitant liver and kidney failure caused by Boichis syndrome, for example, or a liver tumor plus nephrotoxicity.

Of these three groups, primary hyperoxaluria type 1 is the most common indication for combined transplantation. With aggressive pretransplant dialysis and avoidance of posttransplant renal dysfunction, infants who are diagnosed early and receive combined liver-kidney transplant have excellent survival rates. “With the appropriate donor selection, family education, and medical team commitment, combined liver-kidney transplant can be an outstanding option for medical management in this group of patients,” says Clark A. Bonham, MD, surgical director of the Pediatric Living Liver Donor and Intestinal Transplant programs.

“Transplanting more than one organ at once usually increases the time required for the surgery, the stress on the body, and the risk of complications,” says Dr. Grimm. “Patients suffering from liver failure, especially those with methylmalonic acidemia, are often extremely ill at the time they require the transplant. So, the challenge for our highly focused and collaborative kidney and liver teams is significant. Given that, we are proud that in the past 10 years we have had 100 percent patient and graft survival in combined liver-kidney transplants.”
The 4-Pound Fighter

As a premature newborn, Dane went into liver failure and was rushed to Stanford Children’s Health, where—after six weeks of blood transfusions, dialysis, and other life-support interventions—he received a successful liver transplant. Three years later, he also received a kidney transplant. Today, Dane is a happy and energetic survivor.
Vision 2025—Transplant Center Vision and Mission

Vision
To provide the world’s best organ transplantation care to children and their families by a combination of innovation, collaboration, compassion, and perseverance.

Mission and Objectives
To embrace the quadruple aim of care delivery consisting of high-quality care, program growth and cost reduction, meaningful patient experience, and fundamental staff wellness practices.

• Delivering #1 pediatric volumes and outcomes in the nation.
• Leading-edge research, innovation, and educational training.
Transplant Program Contact Information
Heart: (650) 721-2598
Kidney: (650) 498-5480
Liver and Intestine: (650) 725-8771
Lung and Heart-Lung: (650) 498-2568

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